

Summary Findings from 2012 Family Satisfaction Surveys

Completed by DIDD Advocacy Office (now Customer Focused Services Division)

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March 2013

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Survey Findings from the Original Remedial Order Class Members Legal Decision Makers

In early 2012, the DIDD Director of Advocacy Services (now Customer Focused Services) in collaboration with the former Federal Court Monitor's Office, Dr. Nancy K. Ray, conducted a family satisfaction survey of legal decision makers for all living class members who formerly resided at Arlington Developmental Center. The purpose of this survey was to assess the predictors of satisfaction of the families (legal decision-makers) post-closure of Arlington Developmental Center in October 2010. Of the 350 surveys distributed, 196 responses from the legal decision-makers were received.

The predictor variables that were explored to assess family members' satisfaction with community living included the *characteristics of the person who moved* (i.e., sex, age, race, level of disability, medical, physical, and behavioral challenges, date of move, and length of institutional placement) and the *characteristics of the community placement* (i.e., type of provider, size of the provider, and performance on quality assurance reviews).

Based on a 5-point rating scale, satisfaction was assessed using a rating of "good" or "very good," or equal to or greater than 4.

The survey instrument included satisfaction indicators and scales derived from the families' perceptions on 15 dimensions of quality care/services (e.g., health care, safety, staff attentiveness and supervision, residential living arrangement, privacy, meals and snacks, enjoyable daily activities, personal care, protection from abuse/neglect, community activities, dental care, friendships with peers, friendships with staff, relationships with family, and overall quality of life) at both the institution and community settings.

Finally, the survey asked about the things that were most important to family (legal decision-maker) satisfaction with their family members' community home. There were 17 indicators (i.e., good health care, good staff, attention to personal care, good food, good housekeeping, having a job, good housemates, good clinical therapy services, good neighbors that are accepting, community activities, permanence of the home, stable staff, family-like home, ability to attend church, weekend activities, staff who answer my questions, and have a good independent support/service coordinator).

Despite the initial opposition to the closure of ADC and the trepidation relative to the transition process and community placement, the findings from the survey revealed that families were satisfied with community placement (84% of the respondents).

A Statistical Package for Social Science (SPSS) software was used to analyze the data. Specifically, a linear multiple regression model (Analysis of Variance) was run to

analyze all of the aforementioned predictors. Based on a .05 significance level, the type of provider was the most significant predictor, specifically, Intermediate Care Facility (ICF) placement. ICF placement was the only significant predictor variable ($p = .002$) of the legal decision maker's satisfaction. None of the other variables were significant or impacted the predictive relationship between family satisfaction and community placement. In addition to the linear regression analysis, a correlation matrix was run. The results revealed that the quality performance of the community provider agency, although not a significant variable, was a correlate of families' satisfaction. *Of note, the quality performance of the providers was assessed using their average Community Status Review (CSR) scores for two years ($p = .458$) and the average of the Department of Intellectual and Developmental Disabilities (DIDD) quality assurance score for the past two reviews ($p = -.234$).¹*

Furthermore, the survey findings of the 196 respondents revealed the top five factors that were the most important areas of the families' satisfaction with community placement were: good health care ($N = 169$), good staff ($N = 154$), attention to personal care ($N = 111$), stability of staff ($N = 93$), and good clinical therapy services ($N = 63$).

In an effort to assess the overall performance of DIDD and progress with the community service system, many families also provided comments on the survey relative to any recommendations they had for community services for persons with intellectual disabilities in West Tennessee. Although some families' comments elaborated on their satisfaction, others provided details about their concerns.

Positive comments included, but were not limited to:

- Family member could not be happier with current community home.
- Everything seems to be good.
- Like home and staff.
- In 2011, quality of DIDD and leader Jim Henry and persons involved in family member's...now has the best quality of life ever.
- Staff working is great, family member always neat and clean.
- Although did not want Arlington to close...very happy with provider.
- Community has been good because loved one is closer to home.
- Agency has been wonderful to family member.
- Just keep up the good work.
- It was my happiest day when my daughter walked into new home and away from ADC...No complaints.
- Family member is happy and I am happy.

¹ *DIDD Quality Assurance Reviews do not include a review of any of the ICF/IDD programs; therefore, a correlation matrix was run for quality performance of providers and it was not included in the multiple regression analysis.*

- Agency and staff doing a fine job because I am 84 and there is no one else to care for him.
- I think the move to a community home has been positive.
- I thank God for agencies and providers for people with disabilities.
- Good move for my loved one.

Despite the variation in concerns provided, there were some common thematic schemes.

- Providers need to work on communications.
- Communication with family is poor.
- Conservators are not informed of health problems.
- There are no opportunities for jobs.
- There are no ideas for new activities or menu items or community activities.
- Too much time in the homes.
- Services have been cut and it is impossible to manage if no money or health care.
- State of Tennessee has made life very difficult ...cutting funding every year.
- Housing stability is an ongoing concern due to funding cuts that threaten the quality of housing.
- There should be thorough background checks for all staff.
- Most of the staff are just there to get a paycheck.
- Too much money is being spent on shopping.
- Limited services and activities in small rural areas.
- Need better supervision and management in the home.
- Staff turnover due to jobs not desirable.
- Training of staff on person's disability.
- Takes too long to get services through the State.

Some of the recommendations from the families included, but were not limited to:

- Continue Independent Support Coordinators (ISCs).
- Continue and increase amount of the State housing subsidies.
- Continue investigation of suspected abuse/neglect and follow-up resulting provider agency employee disciplinary actions and recommendations of Abuse Neglect Prevention Committee (ANPC).
- Very important to continue operation of the State-operated ICF-ID homes.
- Continue death reviews.
- More neurosurgeons who will take care of shunts.
- A resource guide and/or updated website for free, low cost community activities.
- Higher wages for direct support professional to attract a higher quality employee pool.

- Due to staff turnover, recommend an incentive program is put in place for employees...more pay and health insurance.
- Build a better network of community medical professionals (doctors, dentists, etc.).

Survey Findings from At Risk Class Members Legal Decision-Makers

In addition to the family satisfaction survey of the original Remedial Order class members conducted in early 2012, as part of the Customer Focused Government Initiative, the DIDD Advocacy Director (now the Division of Customer-Focused Services) conducted a satisfaction survey of legal decision-makers of at-risk class members in West Tennessee regarding community services in mid-summer 2012.

The surveys were mailed only to the legal decision-makers of the at-risk class members. It is important to note that there are several at-risk class members that are deemed legally competent; therefore, the surveys were mailed to them. The anticipated response rate was at a minimum 50%. However, after almost four months, only 13% of the surveys were returned. Due to the low response rate, a statistical analysis of the data was not completed, instead each response was tallied.

The first question on the survey instrument assessed if the at-risk class member received services from DIDD. The survey instrument also included satisfaction indicators and scales derived from the legal decision-makers' perceptions on 13 dimensions of quality care/services (i.e., health care, dental care, safety, staff attentiveness and supervision, residential living arrangement, privacy, meals and snacks, personal care (bathing, dress, toileting, etc), protection from abuse/neglect, community activities, friendships with peers, relationship with families, and overall quality of life).

Using a 5-point rating scale for the aforementioned items, respondents were asked to choose the scale that best describes how he or she felt ranging from "very poor" to "very good," regarding their satisfaction about the community home, about housemate(s), and about the level of decision-making in the plan of care for the person in services. Finally, based on hierarchy of importance, the survey assessed the five things that were most important to the legal decision-maker (family or class member) satisfaction with the community placement relative to quality of life. There were 18 indicators (i.e., good health care, good staff, attention to personal care, good food, good housekeeping, having a job, good housemates, good clinical therapy services, good neighbors that are accepting, community activities, permanence of the home, stable staff, family-like home, ability to attend church, weekend activities, staff who answer my questions, have a good independent support/service coordinator, and have a good advocate).

As a result of the 84 surveys returned, the responses revealed that 68 of the 84 (81%) class members were receiving services through the DIDD system; five (5) class members were not in services; three (3) class members were not interested in receiving services

through DIDD; and eight (8) responded they did not know enough about DIDD services to make a decision. Of note, sixteen (16) of the returned surveys did not include responses to questions, thus, the forms were blank. Therefore, the findings of the surveys were based on 68 respondents.

After tallying the responses to each of the 13 indicators that assessed the class members' care and services through DIDD, the top five areas that were rated "very good" were selected. These areas include: relationship with family ($N = 45$), community activities ($N = 41$), and residential living arrangements, privacy, and protection from abuse/neglect were all the same ($N = 37$).

Notwithstanding the areas that were rated "good" or "very good;" there were some areas that were rated "poor" or "very poor." Two (2) respondents rated dental care as "poor" and two (2) respondents rated residential living arrangements as "poor." Also, three (3) indicators were rated as "very poor." These areas were protection from abuse/neglect (one respondent), friendships with others (one respondent), and relationship with family (two respondents).

For the most part, the 68 respondents (legal decision-makers) were satisfied with the community home, housemates, and level of decision-making in plan of care.

Overall Comments

The above findings from the family satisfaction surveys have many implications for positive change to broadened awareness of the importance of an improved service delivery system which can lead to improved quality care and increased quality of life for persons with intellectual and developmental disabilities (IDD). This is imperative, mainly because this population is most at risk of less quality of life due to their inability to strongly advocate for themselves. Yet, they generally have the highest support needs. Therefore, legal decision-makers have become an integral part of the transition process to ensure the best interests of their family member are truly addressed.

The findings have relevance for provider agency administrators, state officials, Parties to the Federal lawsuit in Tennessee, and other stakeholders, particularly in understanding the circumstances that families deem as important in order to improve quality of life and services for persons with IDD. In essence, input from families is critical and serves as an invaluable resource for successful moves to community-based living. Additionally, given that the overall intent of community-based residential placement is to improve quality of life for this population, a quality assurance program is the vehicle by which this goal can be accomplished.

Overall, although the survey findings revealed that families/legal decision-makers were satisfied with community placement, the hope is that DIDD officials will utilize the findings, particularly those of concerns to the families, to assist with improving the service delivery system throughout the state of Tennessee.